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# Meeting of Minds

## Final report

Walloon Parliament, 21-23 October 2005



Under the auspices of  
the King Baudouin Foundation and the European  
Commission



**Sciences du cerveau et société : un débat entre citoyens  
européens**

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**Acknowledgements**

The citizens on the panel wish to express their gratitude to the persons who kindly accepted to act as our resource persons at the third National meeting, as well as to the members of the consultative committee.

**Presentation of the panellists**



Carlo, Renée, Arno, Martha, Marc, Jean-Marie, Madeleine et Laurent.

**Carlo**

My name is Carlo Ardizzone, I am 34, was married at 20 and have two children - boys of 5 and 7 years

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old. I am a postal employee, a postman in fact. I was very interested and attracted by the idea of being selected as a citizen, without knowing anything about neuroscience. At first, I was especially keen on the idea of improving my medical knowledge, particularly on the subject of hyperactivity, a problem of particular interest to me as a father. After the first meeting, I must admit that I found it difficult to follow the discussions but I have now learnt a lot and am proud to have had this experience.

**Renée**

I have always taken a great interest in research, health, well-being and quality of life. I worked as a nurse/social worker for the ONE (National Child-care Office) and later in a Psycho-medical and social Centre. I am now retired and a "darling" grandma, watching my granddaughter's brain develop and hoping it will be open to the world around her, as a citizen. It was the chance of a lifetime to take part in a national and European panel and voice my opinion on neuroscience developments. I am keen to follow the progress in mind-science since my brain is what I am today and what I shall be tomorrow!

**Jean-Marie**

I am married with a son of 30. I have been working for eleven years as a prison officer in Verviers, « as a vocation of course ». Previously, I worked for 28 years in the transport service, as a customs declaration official, until the frontiers were abolished. My present job leaves time to read and take an interest in various things, so I am very pleased to have taken up the invitation for the neuroscience meetings.

**Arno**

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I am 43, unmarried, German-speaking and work at Forem Formation (a re-training centre). Taking part in this project is a unique experience for me, not only because it is the first time there is a science-citizen dialogue at European level, but also because brain-science is a subject which affects us all in the course of our lives.

The discussions that took place during the national and European panels were very rewarding and made me deeply interested in the question. On a personal level, moreover, friendly relationships developed among us.

**Marc**

I live in Tilly, a village belonging to Villers-la-Ville in Walloon Brabant. I live with Brigitte and her little boy, Julien. On August 25th, our son Gabriel was born, making me a proud father.

I studied science and have now been working for over ten years as a police inspector.

Taking part in this neuroscience project is the chance to share my opinions on the subject and I hope to make my voice heard as a European citizen. It has also made me realize that citizens from other European countries have anxieties similar to mine. Our countries have everything to gain from this type of initiative and I am very grateful to the organisers.

**Madeleine**

I live at Horion-Hozémont; I have one daughter and two granddaughters. I retired 5 years ago from primary school teaching, having worked as a teacher and later as head of school.

My participation in the neuroscience panel has given me the opportunity to realize the complexity of the brain and to voice a citizen's opinion on the numerous issues raised.

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**Martha**

My name is Martha. I am married, with two children and a grandson. As both employee and self-employed, I have now retired. Since the age of 58, I have been entitled to 66% invalidity benefit, though I am still able to walk and cycle. I have been deeply affected by Alzheimer's disease, which has struck in my close family. An adequate knowledge of certain difficulties and the possible remedies makes it easier to cope with certain misfortunes. This is what made me eager to take part in this experience. Thanks to these meetings I realized how brain-science was going to change the lives of individuals in society. The information we were given on new neuroscience developments was very rewarding and raised a multitude of questions.

**Laurent**

I am father to two boys, Gaël and Sylvain, and work as an information technologist in the Brussels region. I consider it a great opportunity for me to take part in a project such as this since it gives me the chance to play a true role as a citizen.

Out of 4,000 invitations sent, 127 persons responded expressing interest in the initiative. Among these, 72 persons were willing to participate as panellists and 55 simply wished to be informed of the results. Out of the fourteen citizens selected, one did not attend, two dropped out in the course of the proceedings (after the first European convention) and three were unable to attend for family reasons.

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**Presentation of the Initiative**

**Introduction**

Meeting of Minds is a two-year pilot project conducted by a European panel of 126 citizens. The initiative was launched in 2004 by a group composed of different institutions among which are: the King Baudouin Foundation (co-financer and coordinator of the project), University of Westminster (United Kingdom), Vlaams Instituut voor Wetenschappelijk Technologisch Aspectenonderzoek (Belgium), Danish Board of Technology (Denmark), Cité des Sciences et de l'Industrie (France), Stiftung Deutsches Hygiene-Museum (Germany), IDIS-Foundation - Città della Scienza (Italy), Rathenau Institute (The Netherlands), Science Museum (United Kingdom), University of Debrecen (Hungary), Eugenides Foundation (Greece), and l'Université de Liège (Belgium). This project was also supported financially by the European Commission.

**Belgian specificities**

The Belgian arm of this project was composed of a Flemish and a Walloon panel.

The Walloon initiative is inspired by SPIRAL (*Scientific and Public Involvement in Risk Allocations Laboratory - ULG*), which is a research centre in the field of risk analysis and public involvement. The centre encourages democratic methods of deliberation on scientific progress and technological innovation. The University of Liege shares responsibility for the Belgian contribution to this project with the Flemish Institute for the Evaluation of Scientific and Technological choices.

**Who are we working for?**

This project is an initiative set up by the King Baudouin Foundation and the 11 institutions in partnership. Aware of the importance of the issues, both individual and societal, concerning the development of mind science, the twelve partners



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proposed supporting this initiative to the European Commission.

The results of this first European mind science panel will be communicated not only to the political authorities concerned but also to the whole scientific community.

Thanks to this approach, the *Meeting of Minds* project hopes to respond to the wishes of the European authorities: involve the public in debating the future of scientific research, technological choices and governing principles.

**What are the objectives of *Meeting of Minds*?**

The general objective of the *Meeting of Minds* initiative is to involve European citizens in discussion of and public reflection on neuroscience issues with research workers, political authorities, ethics specialist, various actors involved in this field, as well as representatives of European decision-making organisations.

As such, this project aims to furnish relevant elements for decision-making to European political authorities and to widen the public debate on the subject of neuroscience. It will also help to put neuroscience issues on the agenda at political level. In this respect, the report drawn up by the Walloon citizens will be solemnly presented to the Walloon political authorities on the occasion of an official reception organized on the premises of the Walloon Parliament.

*Meeting of Minds* will make a contribution to developing new forms of social debate and decision procedures at European level.

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**CHAPTER I:**

**Preamble to the six subject chapters**

For each subject, the citizens, at the second national meeting, identified specific questions to be asked of the resource persons. These questions are mentioned in each subject chapter.

The resource persons selected by the organizers and consultative committee (see annex 2) are as follows:

Jean-Pierre CLOSON, Centre Fédéral des Soins de Santé, Assistant Director General.

**Questions asked:**

- Will public authorities always be able to afford freedom of choice?
- What measures are being taken to ensure freedom of choice?
- How can a cost-benefit estimate, as complete as possible, be obtained?
- Does the INAMI (Institut National d'Assurance Maladie-Invalidité) not have a tendency towards one-type medical treatment?
- Is the State able to accept and to afford alternative methods?

Philippe KINOO, assistant senior registrar, paedopsychiatric unit, Cliniques Universitaires Saint-Luc.

**Questions asked:**

- Do criteria for normality already exist? If so, what are they?
- The underlying question is who is to decide what is « normal »; how could a model be decided on? on the basis of what criteria?

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- Are there any schools that apply the latest neuroscience developments?

Christian LEONARD, Head of "Research and Development" department at the "Alliance Nationale de la Mutualité Chrétienne".

**Questions asked:**

- Is there a citizens' involvement in the elaboration of regulations guaranteeing free access to health care? (How transparent is this?)
- What is offered by the State in the way of institutional financial and human support for behavioural handicaps? What is the European position in this respect?
- Is there any possibility of reducing economic pressure from pharmaceutical companies?
- What measures have been put in place by the government up to now?
- What is offered by the State in the way of institutional, financial and human support for behavioural disorders?
- Has the State any means of imposing a certain direction on research? Does the orientation of research take into consideration the question of equal access to treatment in the future?
- Will public authorities always be able to afford freedom of choice?
- What measures are being taken to ensure freedom of choice?

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Paul LIEVENS, Emeritus Professor, Université Catholique de Louvain, psychiatrist and President of the Fédération des associations Similes francophones.

**Questions asked:**

- Is there a citizens' involvement in the elaboration of regulations guaranteeing free access to health care? (How transparent is this?)
- What is offered by the State in the way of institutional financial and human support for behavioural handicaps? What is the European position in this respect?
- Are there any bodies checking on research results?
- How are you informed about developments in the field of neuroscience?
- Is there any possibility of reducing economic pressure from pharmaceutical companies?
- What are the chances of finding the right drug for a disease?
- How long does it take to finalize a drug?
- What is the actual cost of producing a new drug for the market?
- How do doctors deal with medical sales representatives?
- Has the State any means of imposing a certain direction on research? Does the orientation of research take into consideration the question of equal access to treatment in the future?

Jean-Marie MALOTEAUX, neuropsychiatrist, Professor of pharmacology, Université Catholique de Louvain,

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member of the Consultative Bioethics Committee of Belgium.

**Questions asked:**

- What ethical constraints are acceptable for research and treatment?
- Is there an ethical framework covering this area?
- Is there a European ethical framework?
- Who can draw up such a framework?
- How is this framework put into practice?
- Are there any bodies checking on research results?
- What are the chances of finding the right drug for a disease?
- How long does it take to finalize a drug?
- What is the actual cost of producing a new drug for the market?
- How is it that certain drugs are sometimes taken off the market?
- Has the State any means of imposing a certain direction on research? Does the orientation of research take into consideration the question of equal access to treatment in the future?

Robert POIRRIER, Head of the Centre for the study of sleep and waking disorders (Centre d'étude des troubles de l'éveil et du sommeil), CETES-CHU de Liège and joint head of Department of Neurology.

**Questions asked:**

- Is there any danger in having too much information or brain-stimulation?

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- Are there any side effects from receiving a flow of information? What impact do the mobile phone and other electro-magnetic waves have on the brain?
- What impact does the use of the Web have on the brain?
- What sort of research is being done on this subject?
- Western societies are facing the same problems as us. Is research concerned with these problems? If so, what aspects are being examined, and how?

Eric SALMON, Liege University Hospital Centre, Department of Neurology, Memory Centre and Medical Imagery Research Centre.

**Questions asked:**

- What can be read from medical brain-imagery? (connection with normality/diversity, freedom of choice and regulation)
- How do doctors deal with medical sales representatives?
- According to what criteria can a person be considered incapable of making a choice?
- At what point, for what reasons and under what conditions can a person be forced to undergo a treatment?
- Will public authorities always be able to afford freedom of choice?
- What measures are being taken to ensure freedom of choice?
- What is the present orientation of research?

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- Western societies are facing the same problems as us. Is research concerned with these problems? If so, what aspects are being examined, and how?

Geneviève SCHAMPS, Professor of Medical Law, Catholic University of Louvain. Vice-President of the « Patients' rights » Federal Commission.

**Questions asked:**

- What ethical constraints are acceptable for research and treatment?
- Is there an ethical framework covering this area?
- Is there a European ethical framework?
- Who can draw up such a framework?
- How is this framework put into practice?
- Are there any bodies checking on research results?
- According to what criteria can a person be considered incapable of making a choice?
- At what point, for what reasons and under what conditions can a person be forced to undergo a treatment?
- Will public authorities always be able to afford freedom of choice?
- What measures are being taken to ensure freedom of choice?

## **CHAPTER II** **Regulation and control**

### **1) Our understanding of the matter**

We consider it necessary to draw up regulations/laws concerning the following:

- Guarantee of free access to health-care;
- Protection in case of error;
- Ensuring the impartiality of results provided from research papers with regard to treatment;
- Checks on the content of information (publicity);
- Setting-up of support facilities for the patient's family in order to improve the patient's all-round conditions;
- Confidentiality of data concerning a patient;
- The patient's right to be informed of the diagnosis for his case;
- Protection of private life: refusal of state of health questionnaires for obtaining employment, insurance or a loan...

Ethics.

An ethical framework is necessary in the fields of research and treatment. This ethical framework should not be rigid but should be able to evolve with evolution of society.

### **2) Our sources and their impact**

#### **2.1.) What were the questions asked of our resources persons?**

- 2.1.1- What ethical constraints are acceptable for research and treatment?
- 2.1.2- Is there an ethical framework covering this area?
- 2.1.3- Is there a European ethical framework?
- 2.1.4- Who can draw up such a framework?
- 2.1.5- How is this framework put into practice?



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2.1.6- Is there a citizens' involvement in the elaboration of regulations guaranteeing free access to health care (How transparent is this?)

2.1.7- What is offered by the State in the way of institutional financial and human support for behavioural handicaps? What is the European position in this respect?

2.1.8- Are there any bodies checking on research results?

**2.2.) What essential points have we learnt?**

• **Legal framework**

We are pleased to learn that there exists in Belgium a recent legal framework:

- o On patients' rights, in particular the right to be told or not to be told;
- o On the checking of research in the pharmaceutical industries.

This legal framework is not, however, sufficiently well-known (informing the public).

Some of us consider the legal framework too complex and too hard to apply.

• **Ethical framework**

- o We are pleased to know that ethics committees exist at local level (in each hospital and research centre) as well as at national and international level.

• Link between ethics and laws: ethics are of no legal value.

• Delicate balance between individual interests and the interest of society: the objective of social security is to care for society and laws aim to protect the individual.

• We have learnt that further training of doctors in the latest neuroscience developments is not compulsory.

**2.3) Changing opinions**

• We were very apprehensive but have been reassured:

- o to know that there are checks on research
- o that there is legislation to ensure the rights of the patient.

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**3) Our conclusions**

**Legal framework:**

- There should also be directives at European level.
- Doctors should be well trained from the legal and ethical points of view.

**Checks on research:**

- Neurological disorders being peculiar to humans, certain forms of experiment can only be carried out on a human being: they must therefore be regulated and made safe. Some of us do not accept all the forms of animal testing.
- Ordinary citizens should take part in committees for checking research.

**Ethics committees:**

- Ethics committees should also be composed of ordinary citizens.
- The work of ethics committees should be transparent (open to inspection by ordinary citizens).
- Some of us (but not all) consider it necessary to set up consultative committees on research orientations and their financing.
- A bio-ethics committee dealing with neuroscience:
  - should have consultative value;
  - should have a legitimate mandate if its opinion is compelling.
- **Transparency of political decisions** concerning neuroscience: the decisions must be motivated.
- **Self-criticism:** some of us think that attention should be paid to keeping open the possibility of self-criticism. For example, in the last century, atrocities were committed in psychiatric asylums. What are we doing to avoid inappropriate procedures at the present time?
- Some of us regret that in the legislation the right to know is incomplete, in particular respecting the doctor's discretionary power to withhold information.

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CHAPTER III  
Normality or diversity

1) Our understanding of the subject

We prefer diversity to normality, with regard to both individuals and treatments. Diversity is important for progress, for innovation and for improving humanity (cf. direction of the history of societies). Neuroscience should therefore take this aspect into consideration.

The definition of « normal » and its use can lead to abuse (e.g. The Holocaust). Rather than abnormality, we prefer illness.

There are those who think it necessary to have markers/criteria for « normality » in order to help people (to live in society?), to help people who are excluded to function within society. In this case, the underlying question is who will decide what is « normal » and how will the model be decided on.

There are others who consider that a sick person may be a symptom of a sick society. According to this hypothesis, is it the individual or society that is abnormal?

It is the person him/herself who should decide if he/she is sick. In the case of incapability (in the wider sense: medical, educational, legal...), it is for the immediate entourage, with the help of doctors, judges and/or others, to make the decisions (in connection with "freedom of choice").

The underlying question is who will decide what is « normal » and how will the model be decided on? On the basis of what criteria?

2) Our sources and their impact

**2.1.) What were the questions asked of our resources persons?**

2.1.1- Do criteria for normality already exist? If so, what are they?

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2.1.2- The underlying question is who will decide what is « normal » and how will the model be decided on. On the basis of what criteria?

**2.2) What essential points have we learnt?**

Normality is not indefinable, and yet it can be identified by what it is not. For example, illness is not a criterion of normality.

Drawing up general criteria for normality is dangerous since there is risk of exclusion and stigmatisation. Normality cannot be regulated; no legislation or ethical definition is acceptable in this case.

**3) Conclusion**

Scientific research in the field of neuroscience cannot, any more than in any other scientific discipline **define what normality really is**. And yet, criteria for medical normality are necessary, though not necessarily sufficient, in order to improve **individual well-being**.

We wish to avoid « **hypermedicalisation** of « abnormality » and rather to favour **solidarity**.

The impossibility of drawing up a definition of normality supposes a **tolerant** attitude.

## CHAPTER IV

### Information, education et public awareness

#### 1) Our understanding of the subject

We demand high quality up-to-date information for:

- better understanding, knowledge and decision-making (prevention and treatment);
- avoiding manipulation.

This high-quality information should be available as widely as possible to ordinary citizens (for example, on a public television channel, by widely distributed leaflets, ...).

The educational world, both pedagogic and paramedical, should be opened up to the benefits of new neuroscience developments for teaching.

Recent knowledge in neuroscience which influences ways of approaching children should be taught (further training) in pedagogic and paramedical spheres. For example, with small children, the environment should be as appropriate as possible (well-being and love factors).

We wish to see neuroscience information sessions in schools (connected to quality of information on regulation and control).

We are concerned about the effects on the brain of the media in the environment. Neuroscience results should be used to improve this environment. Parents should be systematically informed of this negative effect (nicotine-addiction, violence, obesity,...)

Information on hygienic living and its influence on the brain is essential: tobacco, stress, diet, sleep, ...

Adults should be made aware of the problems in order to re-learn a sense of responsibility (cf. fashion and manipulation phenomena).

It is important for doctors to be aware that there is an unequal conflict between information provided by the pharmaceutical industry and other sources of information.

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**2) Our sources and their impact**

**2.1.) What were the questions asked of our resources persons?**

2.1.1- How are you informed in the field of neuroscience?

2.1.2- Are there any schools that apply the latest neuroscience developments?

2.1.3- Is there any danger in having too much information or brain-stimulation?

2.1.4- Are there any side effects from receiving a flow of information? What impact do the mobile phone and other (electro-magnetic) waves have on the brain?

2.1.5- What impact does the use of the Web have on the brain?

**2.2) What essential points have we learnt?**

It is fundamental to have a critical attitude and advisable to be suspicious of expert opinion. According to Belgian law, the doctor is not obliged to inform the patient about his state of health if he considers that the information provided might further damage the patient's health.

It is difficult to inform people about neuroscience, in spite of the fact that everyone is concerned, whereas it can be so easy to inform the population about questions that do not directly concern the individual (example: disasters abroad,...).

**3) Conclusion**

The issues raised by the science of the brain are of interest to few people. More widespread interest should be **stimulated by different media**.

It is important for the public as a whole to be informed about neuroscience knowledge. The **general practitioner** is the main purveyor of information and should be recognised as such. This knowledge should be made accessible and circulate among **all education and training institutions**.

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A **critical attitude** should be taught to children at the earliest age.

**The media environment and its effects on the brain** are of concern to us. Neuroscience research results should be used to improve it. Parents should be systematically informed.

On the basis of neuroscience knowledge, some of us recommend imposing a tax on the **negative externalities** (advertising, violence, nicotine addiction, ...) in order to improve the quality of television programs.

CHAPTER V

Pressure exerted by economic interests

**1) Our understanding of the matter**

Researchers, doctors and patients must be independent of economic pressures exerted either by pharmaceutical companies or by the State. We refuse to accept that certain treatments be « compulsory » to be eligible for (part) reimbursement or in order to hold the right to a certain treatment or support.

The relationship between the pharmaceutical industry, the State, scientists and doctors should be made transparent.

There should be a guarantee that a stronger economic group does not overwhelm other actors who may be in competition.

There should be a limit to pharmaceutical companies' means of advertising to medical practitioners.

The media should be screened for the messages, whether plain or covert, they convey (e.g. Super-Me, a social model imposed on the family..).

For some of us, in the field of neuroscience, medical imagery plays an important part: we consider that it must be used when necessary for diagnosis. There exists at present, however, an obligation to take profitability into account. Such an obligation should not exist in the field of medical treatment.

For others, the return on investment in medical equipment has to be taken into consideration.

The working community should encourage integration of unwell persons into working structures. There can be no pressure on unwell persons who are capable of becoming autonomous.

Each of the actors (political, pharmaceutical, medical and nursing,...) bears part responsibility for economic pressures. A wide-ranging debate should be held on this subject.



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**2) Our sources and their impact**

**2.1.) What were the questions asked of our resources persons?**

2.1.1- What can be read from medical brain-imagery? (connection with normality/diversity, freedom of choice and regulation)

2.1.2- Is there any possibility of reducing economic pressure from pharmaceutical companies?

2.1.3- What are the chances of finding the right drug for a disease?

2.1.4- How long does it take to finalize a drug?

2.1.5- What is the actual cost of producing a new drug for the market?

2.1.6- How is it that certain drugs are sometimes taken off the market?

2.1.7- How do doctors deal with medical sales representatives?

**2.2) What essential points have we learnt?**

We live in a paradoxical world. On one hand, research is carried out to improve general well-being while on the other, products are allowed on the market that are harmful to the brain.

Neuroscience is concerned in one new drug in five. The production process for a (truly innovative) new drug takes between 10 to 14 years.

The pharmaceutical industry puts a high level of investment into research, but it must be pointed out that marketing investment is even higher.

The production of new molecules causes the « production » of new pathologies : risk of hypermedicalisation.

For some of us, the impact of pressure from the pharmaceutical industry on the medical community is less intense than they thought it was.

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In the medical community, certain categories are more subject to economic pressure than others (for example, general practitioners are less subject to pressure than hospitals).

**3) Conclusion**

It is important to hold the **balance between different powers** (pharmaceutical companies, doctors, citizens, media). This supposes, as well as a critical attitude on the part of the citizen, a balance between:

- profit for the pharmaceutical industry;
- affordability for public authorities;
- freedom for doctors;
- means of guaranteeing neutrality in the media.

**As consumers**, we are aware that our buying-power can constitute a counter-weight to pressure from the pharmaceutical industry (For example, the use of generic drugs).

Social security must protect citizens and we consider that the creation of a high-quality European system of social security would be able to provide a more effective counter balance to economic pressures.

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**CHAPTER VI**

**Equal access to treatment**

**1) Our understanding of the matter**

The subject is important for us as it is essential to facilitate access to treatments. Some of us consider that there should be a guaranteed right to treatments for everyone. We wish to avoid a two-tier society.

A system of access to health care should be put in place at European level.

Ease of access should not limit the offer.

State-financed research should not be selected according to economic criteria but for the general health benefit.

**2) Our sources and their impact**

**2.1.) What were the questions asked of our resources persons?**

2.1.1- What measures have been put in place by the government up to now? What is offered by the State in the way of institutional, financial and human support for behavioural disorders?

2.1.2- Has the State any means of imposing a certain direction on research? Does the orientation of research take into consideration the question of equal access to treatment in the future?

**2.2) What essential points have we learnt?**

The European Union provides financing for research on rare and little-known disorders.

**3) Conclusion**

In Belgium, **we enjoy a very high level of access to treatments**, thanks to doctors, available equipment and collective financing. We would like to see a **European harmonisation at this high level**.

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**CHAPTER VII**

**Freedom of choice**

**1) Our understanding of the matter**

This aspect is of the greatest importance to us. There are, however, certain pitfalls to be avoided.

Avoiding one-track thinking.

We find it important to preserve diversity of approach to the solutions proposed so that the patient and family have the chance to choose methods of treatment, the doctor and the application of the treatment. This raises the question of quality of information (cf. subject 3) and the question of financing (cf. subject 5).

Respect for confidentiality

Framework.

Decisions of great consequence have to be made. A suitable framework is, in our opinion, essential. Important precautions (dialogue and protection) are necessary before any intervention and these should involve (in order of importance) the individual, the family, medical practitioners and social services. These are our reasons : we wish to be able to make a well-informed decision. When patients are unable to decide for themselves, their entourage (in the wider sense) should, with all the necessary information, be able to decide for them.

Financial resources.

Financial resources should be shared out in order to guarantee diversity in research. Such resources are a necessary condition for freedom of choice.

Ethics.

We consider it necessary to have an ethical code drawn up for research (see regulation).

Education for responsibility.

It is essential for all to bear responsibility in any decision-making process.

## **2) Our sources and their impact**

### **2.1.) What were the questions asked of our resources persons?**

2.1.1- According to what criteria can a person be considered incapable of making a choice?

2.1.2- At what point, for what reasons and under what conditions can a person be forced to undergo a treatment?

2.1.3- - Will public authorities always be able to afford freedom of choice?

2.1.4- - What measures are being taken to ensure freedom of choice?

2.1.5- How can a cost-benefit estimate, as complete as possible, be obtained?

2.1.6- Does the INAMI not have a tendency towards one-type medical treatment?

2.1.7- Is the State able to accept and afford alternative methods?

2.1.8- - What sort of research is being done on this subject?

2.1.9- Western societies are facing the same problems as us. Is research concerned with these problems? If so, what aspects are being examined, and how?

### **2.2) What essential points have we learnt?**

We are reassured to know that legislation exists (for example, the May 7th 2004 law: Human persons regulation) which protect our fundamental liberties. These laws are not known to all. For example, we did not all know of the existence of a "health representative".

We also learned that in certain exceptional circumstances, it is possible to override a citizen's decision to refuse treatment (for example, an insane person).

We consider it useful to collect data concerning the treatments provided to the population. In Belgium, the Federal Centre for health-care expertise can, for

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specific diseases, identify each doctor's prescriptions and inform those who prescribe very differently from the average. This can be of great help to doctors but we must guard against denying their freedom of treatment. Some of us express serious apprehension.

### **3) Conclusion**

It is essential **to be well-informed in order to make the right choice**. We could bring our influence to bear on society by being more critical **and more responsible as consumers** (medicines, treatments, tobacco, alcohol, ...). Not all our problems necessarily need drug-treatment.

To be able to choose, it is of the greatest importance to preserve **diversity of treatment**.

Everyone's **quality of life** should enable him or her to maintain a good standard of health.

**The INAMI and the mutualities** should persevere in their efforts to guarantee freedom of access to health-care. We consider that a high-quality European system should be set up. We consider it essential, however, that **doctors** should continue to be allowed complete freedom in their treatment of patients.

**Transparency** is absolutely essential in the process of **decision** as well as in decisions taken by political entities concerning public health.

The institutions responsible for collecting medical data should have the means to be **impartial**.

In order to ensure the highest measure of freedom of choice, we propose that **set forms** should be available for citizens to fill in (for example, refusal of consent).

**Chapter VIII:**  
**How are we going to use our new knowledge of brain-science?**

**Informed choices**

- keeping myself informed on existing legislation.
- Having a better knowledge of legislation for the protection of the patient and the individual.
- Reflecting personally on the "trustworthy" person and the representative who could look after my interests in the future.
- I shall wait for the new information leaflets on the decisions to be taken at the end of my life and spread this information around.
- I shall think about not letting myself be influenced by other people in making the decision whether to accept treatment or not (in a serious case).
- When problems arise, I will seek treatment in a hospital practising the latest developments in medicine.

**Quality of life**

The brain needs rest and hours of sleep: the quality of sleep depends on our living conditions: I will pay attention to this.

- I will try to sleep longer and better in order to improve my memory and find solutions.

**Appreciating diversity**

- By being more tolerant towards certain of those around me who voice complaints.
- I shall accept that certain persons suffer from medical disorders.

**Informing people**

- By speaking of my experience to those around me.



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ANNEX 1

Program of the Third National Meeting

Saturday 22 and Sunday 23 October 2005 -  
Walloon Parliament

Objectives:

The objective of the third national meeting was to hear the answers of the resources persons to the questions identified by the Walloon panellists during the second national meeting (Coxyde, 23-25 September). The panellists, armed with this new information, could then draw up their final report.

On the Saturday, our resources persons answered the questions asked, one by one. They then took part, four at a time, in a round table with the citizens.

Saturday's program:

Time	
8.30 - 8.45	Reception
8.45	Introduction
9.00 - 9.45	Mrs Geneviève Schamps
9h45 - 10h30	Mr Jean-Marie Maloteaux
10.30 - 10.50	Break
10.50 - 11.35	Mr Jean-Pierre Closon
11.35 - 12.20	Mr Robert Poirrier
12.20 - 12.45	Break
12.45 - 13.30	Round Table of citizens and resources persons
13.30 - 14.20	Sandwiches
14.20 - 14.30	Introduction
14.30 - 15.15	Mr Philippe Kinoo
15.15 - 16.00	Mr Paul Lievens
16.00 - 16.20	Break
16.20 - 17.05	Mr Christian Léonard
17.05- 17.50	Mr Eric Salmon
17.50 - 18.15	Break
18.15 - 19.00	Round Table of citizens and resources persons
19.00 - 20.30	Dinner

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ANNEX 2

Consultative Committee

Role and mission:

In order to select resource persons with care, a consultative committee was set up among the organizers of the Walloon panel. The French-speaking members of the latter are as follows: Jean-Louis GENARD (Philosopher, ULB), Bernard ROGISTER (Neurologist, ULG) and Karin RONDIA (Scientific Journalist). In addition to their participation in the drawing-up of the list of resource persons for the third national meeting, the members of the consultative committee also met with the citizens at the second national meeting. During these meetings, the citizens were able to experience for the first time an exchange of views and a dialogue with « experts ».

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ANNEX 3

The organising team

Florence André-Dumont (Athantor-Médiations)

Dr. Sébastien Brunet (Spiral, University of Liege)

Frédéric Claisse (Spiral, University of Liege)

Bernard Cornélis (Spiral, University of Liege)

Concetta Falzone (Faculty of Law, University of Liege)



From its creation in 1995, the SPIRAL laboratory (ULG) specialised in the evaluation, management and communication of risk - major technological risks (e.g. Seveso), natural risks (e.g. radon) and contemporary risks (e.g. BSE). SPIRAL's fields of investigation are therefore predominantly concerned with technological risks, environmental and planning conflicts, public health protection and food risks. But in addition to this particular type of enquiry, Spiral has developed a more general reflection on the management of public policies (elaboration, implementation and evaluation), improvement in public decision-making processes, institutional expertise procedures, the science/society relationship, improvement in interdisciplinary collaboration practices, public awareness and informing the public on scientific matters and finally the opening-

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up of the scientific community to the preoccupations and points of view of the public. All these developments finally lead to an overall reflection on the fundamentals of democracy (in politics, science and industry) as well as on the new forms of deliberative governance.